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Title: Young people's participation in the development of a self-care intervention – a multi-site formative research study.

Running title: Development of a self-care intervention

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Abstract

The poor outcomes of young people with chronic health conditions indicate that current services and self-care programmes are not meeting the needs of young people. How young people self-manage their condition impacts on long-term health outcomes, but there is little published evidence that details the development of self-care programmes and their most effective components. This paper reports on an innovative formative research study, the purpose of which was to develop a self-care intervention prototype. Participants were 87 young people, aged 12-17, and seven young adult facilitators, aged 18-25, with type 1 diabetes or asthma. Each contributed to talking groups exploring themes that young people wanted to be addressed within a self-care programme. Instead of being focused on 'illness', young people's main concerns were directed toward 'life as an adolescent', while at the same time building sustainable daily routines of self-care. Overall, this paper illustrates the process of initiating and implementing a developmental approach focused on young people, while also demonstrating the tailored self-care intervention that the process developed. This approach can be used to involve young people in the design and development of other conditions that rely on self-care interventions.

Word count: 190

Introduction

Chronic conditions among young people represent a major public health concern [1]. In the UK, over 20,000 young people have type 1 diabetes [2]. A further 1.1 million young people are diagnosed with asthma [3]. Yet, even though the prevalence of type 1 diabetes and asthma in young people is increasing, health and social policy continues to focus on adults. Despite an annual budget of £20.5 billion allocated to chronic conditions, money continues to be spent on addressing failures of self-care, which in themselves signal that services have been delivered ineffectively [4].

For chronic conditions, like type 1 diabetes and asthma, self-care is central to optimising health and well-being. This is because both conditions quickly worsen with short-term lapses in lifestyle routine [5, 6, 7]. However, contemporary evidence indicates that much of the health care designed to facilitate better self-care among young people is doing little to prevent such lapses [8]. This is especially problematic when those patients are children or adolescents, since any harm that results from such emergencies can endure long-term [9]. Further, when lapses create emergencies they incur additional, but essentially avoidable, health care costs [10, 11].

Taking type 1 diabetes as an example, the profound long-term consequences include heart disease, blindness and kidney disease. These complications reduce life expectancy by an average of 20 years [12]. Indeed, young people who develop type 1 diabetes before the age of 15 have substantially worse outcomes than those developing it in later life [13]. Therefore, it is important that young people learn to optimise their blood sugar levels, measured by HbA1c (glycosylated haemoglobin), at values below 7.5% (and above 4% to avoid hypoglycaemia). However, in the UK

fewer than 20% of young people achieve this target and even more alarmingly, 48% do not achieve values below 9.0%, a level where the risk of complications increases substantially [14]. These figures are not only a concern in their own right, but also they offer a clear indication that current services and self-care programmes are not meeting the needs of young people.

Programmes which fail to fully engage young people are likely to reflect unfounded assumptions about young people while at the same time addressing a particular set of needs among practitioners. Programmes such as TRAC, Good2Go and Be Your Own Boss (BYOB) are geared towards young people with chronic conditions in transition from paediatric to adult services [15]. However, and notwithstanding that they incorporate self-care, the programmes are based on assumptions relating to what professionals *think* young people need from a self-care programme. These include generic information on health and lifestyle behaviours and transition issues. None of the above programmes have been properly evaluated and, therefore, it is difficult to assess their effectiveness in terms of health outcomes [15]. Of the limited number of robust evaluative studies that do exist and have demonstrated improvements, it is possible to identify some common characteristics [17]. These include, a focus on the needs of the young person and a disease specific education programme that incorporates self-management skills training [18, 19, 20].

There is clear evidence that the programmes delivering the most impressive self-care outcomes have been developed by carefully attending to the expressed needs of young people [16, 17]. Furthermore, among the 25,000 young people in Germany with type 1 diabetes, a model of care has been used over the past 20 years that places the young person at the centre of their care. The model is holistic in that it

addresses the medical, psychological and social needs of the individual and does not assume that all young people with type 1 diabetes are a homogeneous group with the same requirements. Importantly, this is translated into the care that the young person receives, which is tailored to the lifestyle of the individual and their family. Between 1995 and 2004 this model resulted in an overall reduction in HbA1c figures, with 50-55% of young people achieving an HbA1c of below 7.5% [21]. In the UK, only 14.5% of young people achieved a HbA1c of <7.5 [22].

Despite there being no doubt that how young people adapt to manage their condition will impact on long-term health outcomes [23], there are few published papers that address the development of self-care programmes *and* that detail the emergence of the most effective components of those programmes [17, 24]. Even less research has shown how young people can be purposively involved in shaping and developing these programmes.

Although there are examples of peer-led initiatives both within the UK and elsewhere, and which have been shown to be superior to those led by adults [25, 26], there are none that have enabled young people to lead and decide what their self-care programme should look like. Therefore, this study is unique because both the developmental process, i.e. the process of actively involving young people in establishing a self-care intervention, as well as the resultant intervention, are different compared with previous techniques. There are similar programmes to the study outlined here, namely the BYOB programme in Canada [15] that has been established to manage the transitional care of young people with chronic conditions, but as far as the authors are aware BYOB did not involve the young people in the design and development of the programme. In terms of programme content, the

BYOB programme is again similar in that it is a community-based, peer-led initiative designed to help young people with chronic conditions develop self-management skills through facilitated workshops. In addition, it is tailored towards increasing self-efficacy and promoting independent healthcare behaviours. However, the programme in this paper is different because it is not simply focused on the transition process and the medical aspects of self-management [27]. Rather, it incorporates discussions on a wide range of issues, according to the needs of individuals, their lifestyle and their chronic condition and includes topics on relationships, socialising, parental concerns, school, sporting activities, managing the clinic consultation, etc. These discussions take place within the context of practical, fun-based activities where young people and peer-educators share experiences and learn from each another.

Given the lack of attention focused on formative approaches involving young people, the purpose of this paper is to detail a UK-based project aimed at fully involving young people in developing a self-care intervention for young people with type 1 diabetes or asthma. This is the first study of its kind that has been developed using this innovative approach in the UK. The paper also illustrates the use of this participatory research methodology [28, 29], so providing a template for the development of further interventions.

Method

The starting point for this formative research was the Expert Patient Programme (EPP), which uses a model of lay-led self-management to support people with a long-term, chronic condition. The EPP aims to help people to maintain their health and improve their quality of life [30] and following its introduction as an adult

approach it was recommended that similar provision be made accessible to young people with equivalent long-term, chronic conditions [31, 32]. However, rather than risk adopting an adult model where the framework is designed for adults rather than young people, or arbitrarily creating a self-care intervention programme, a research project was undertaken in 2006 and 2007, focusing on young people, aged 12-17, with type 1 diabetes and asthma respectively. This age range was chosen because of the absence of EPPs specifically for young people aged 12-17 and the variable transition services that exist aimed at young people spanning this age range. The research study aimed to uncover what young people thought an EPP should address to meet their unique health needs and then to collaborate with the young people to develop a self-care intervention that would help them to better manage their condition and improve their overall quality of life.

While the EPP provided a template, formative research was adopted for its appropriateness, since this generates information that is relevant for the development and implementation of a specific intervention [33, 34]. In this case, it was necessary to ensure that the resulting self-care intervention was participant-oriented and tailored to the young people with diabetes or asthma, thereby enhancing the likelihood of the intervention meeting their needs and improving optimal self-care regimens. With this in mind, young people needed to be engaged and working collaboratively to develop the intervention. Therefore, elicitation procedures were used to assess (i) the determinants of young people's behaviours, (ii) the most important factors driving their behaviour and (iii) to create an appropriate client-centred intervention. Whilst type 1 diabetes and asthma are clearly different conditions, their management is underpinned by self-care. As with the adult EPP model the key aspect is the transferability of principles and practice, including peer

support and self-management. Therefore, the program can be developed for any long-term health condition.

Given the exploratory nature of the formative research a qualitative methodology was adopted based on discussion groups, more widely known as focus groups. These groups allowed young people relatively free scope to explore and elaborate on their own views and experiences [35, 36, 37]. Although the same as focus groups, participants preferred to call the focus groups 'talking groups', believing this to be a more accurate portrayal of what they had actually done in their groups. Therefore, the term 'talking groups' was adopted throughout the research.

A purposive sampling approach was adopted to bring together young people to share experiences of living with type 1 diabetes or asthma. Therefore, inclusion criteria were established that incorporated males and females of any ethnicity, aged 12-17, with type 1 diabetes or asthma and living in the research area. In addition, it was necessary to select participants who would be willing to share their personal views and experiences in talking group discussions [38], which necessarily meant that those who had learning difficulties or who were not comfortable participating in a group discussion were excluded. Participants were recruited through 28 secondary schools (pupils aged 11-18) across a wide geographical area, including both rural and urban localities, via two local health authorities. Accordingly, those young people who met the inclusion criteria were identified, along with the schools they attended, by Diabetes Nurse Specialists (DSNs) and asthma nurses working in the two health authorities. Both the diabetes and asthma nurses had links with the schools through the joint care plans, involving health and education, that they helped to establish for the young people. The researchers worked with the DSNs and asthma nurses

initially to recruit eligible participants. Local ethical approval was obtained from the two health authorities where all the schools were located. Ethical approval was not required from each school, although permissions from the head teachers were obtained. Young people and parents were informed of the research by letter. All participants took part voluntarily and provided informed consent; parental permissions were also obtained. No incentive was offered to participate in the research. The first stage of the study involved 41 young people (17 females), drawn from a regional sample of 74 young people registered with type 1 diabetes. In the second stage, 46 young people (23 females) with asthma were drawn from 62 registered patients.

An innovative approach within the study was for young people to facilitate the discussions. Existing evidence suggests that young people relate better to other young people with the same condition, than to health professionals [39]. Therefore, for both stages of the research young adults, aged 18-25 with type 1 diabetes and asthma respectively, were also trained and recruited to facilitate the talking groups. Seven young adult facilitators were trained and recruited, three with type 1 diabetes and four with asthma. These facilitators managed the talking groups, supported by nurses and the principal researcher. The eligibility criteria for the young adult facilitators were that they had either type 1 diabetes or asthma, were aged between 18 and 25, were willing to participate in training and were comfortable facilitating a group. They were recruited according to the same procedures for the young people, i.e. through the DSNs and asthma nurses in the two health authorities. The young adult facilitators attended Leeds Metropolitan University for a 2-day structured training programme that incorporated instruction in safeguarding issues, facilitation of activities and management of groups. The training programme was delivered by a

trainer specialising in active learning and a lead in child protection. The number of groups that each young adult facilitated varied according to their personal commitments and some facilitated more than one group.

A total of 28 talking groups were conducted (15 groups focused on diabetes; 13 on asthma) with between two and six participants per group. All groups were mixed, with 46% females participating overall. The size of the groups depended on the numbers of young people with either diabetes or asthma attending each school. In addition, some young people preferred to talk in pairs or in small friendship groups rather than in a large group. Groups were conducted in schools, predominantly during lunch breaks. Each lasted approximately 1 hour and permission was obtained to digitally record the discussions. A simple schedule was developed to address key areas for the development of a self-care intervention:

- The difficulties of living with a long-term condition;
- The ideal content of a self-care programme;
- The preferred means of delivering a self-care programme.

Verbatim transcripts were analysed by the facilitators working alongside the principal researcher. A growing body of literature centres on the benefits of engaging young people in research [40, 41]. Kellett [42] argues that the "...key to a better understanding of children and childhood is children themselves - as active researchers" (2005, p.3). Therefore, the facilitators were taught simple techniques of content analysis and data reduction [43] to ensure their involvement in all stages of the research, including analysis.

Examples of questions and prompts from the talking groups

What problems or difficulties have you faced living with Type 1 diabetes or asthma? Prompt: What 'bugs' you about having diabetes (asthma)?

Prompt: How does it affect you at home, school?

What topics should a self-care programme include to help support you to manage these problems and difficulties?

Prompt: If you had to write a new programme what would you include?

How, when and where should the programme be delivered?

Prompt: What's the best way for us to deliver the programme, e.g., in a school-type setting, through activities?

Prompt: What are the best times in the week for you?

Prompt: Where would you prefer the programme to be held?

Results

The facilitators identified several main themes in response to the talking group questions. The collated findings from the studies are presented here.

Views on the difficulties of living with type 1 diabetes and asthma

Many young people focused on the practical implications of their condition, especially administering injections (diabetes) and using an inhaler (asthma). Both groups spoke about the inconvenience of having to carry medical equipment and the difficulty of finding somewhere private to administer medication. This was more of an issue among those with diabetes, given their need to find a safe and clean place to

administer injections. However, young people with asthma did not like using their inhalers in public either,

'You feel like you're working your life around it [the condition]'

Asthma talking group, aged 14.

The strong mental and emotional impact of the conditions was a recurring theme. Almost universally, participants spoke about experiencing negative emotions, including anger, worry, embarrassment, and anxiety in relation to everyday occurrences,

'It's so embarrassing if you have to take it [inhaler] in the middle of town'

Asthma talking group, aged 14.

Young people felt that their day-to-day lives were restricted by their diabetes and asthma, especially when they were going out and socialising. All this conspired to worsen their mood. In some cases this led to disengaging completely from activities that their peers enjoyed and, therefore, from friends,

'I can't join a football team because I can't run for long periods of time'

Diabetes talking group, aged 12;

Others, especially older participants (beyond the age of 14), dealt with this by rebelling and deliberately mismanaging their condition,

'I don't use my inhaler anymore. I threw it away cos I got sick of it'

Asthma talking group, aged 15.

Relationships were regarded as very important and many young people reported deriving a huge amount of support from friends. However, while bullying was an

issue in some cases, concerns were more about feeling different and being singled out because of their condition. Their preference was to be seen as individuals in their own right,

‘People focus on my diabetes all the time...I just want them to know who I am’

Diabetes talking group, aged 15.

Difficulties with parental relationships were also highlighted, especially when parents assumed control and failed to listen to their offspring,

‘A lot of arguments as mum wanted to take control ...not allowed to make my own decisions’ Diabetes talking group, aged 13.

This over-controlling behaviour was seen as signalling a lack of trust that young people could manage their condition independently. The young people felt strongly that they needed more independence to control their condition and to show their parents that they could do this. For them, parents could begin to build trust by parents listening to them, as opposed to parents always telling them what to do.

The quality of relationships with health professionals was also raised as an important issue. Whilst there were some positive comments, a large proportion of young people were dissatisfied, highlighting on-going communication difficulties. This is despite the existence of policies encouraging professionals to talk to young people and involving them in decisions regarding their care. Here the concern was that health professionals preferred to ‘talk over’ them to speak to their parents, even when the parents wanted a different approach,

‘They always talk to my dad and ask him about it and my dad will say “Why don’t you ask her?” and then they will look at me, but then ask him again’

Diabetes talking group, aged 16.

'They always think the parents know everything and they are not even going through it' Diabetes talking group, aged 17.

All young people, from both studies, wanted more information and guidance in relation to specific aspects of their condition. Some spoke about a lack of understanding in relation to what was happening to them. Others were confused because they had not been told what to expect short-, mid- or long-term. This knowledge was seen as important for developing self-management skills, especially when things were going slightly awry but could be recovered with timely self-care.

Views on the content of a self-care programme

Young people were extremely positive about having access to a self-care programme aimed specifically at helping them. They highlighted five key topics for programme content. Firstly, they wanted 'condition-dependent information'; this was only rarely discussed with health professionals. A major motivation here was to acquire the level of practical management skills that would allow them to manage their condition so they could 'stay out of hospital'. Staying out of hospital was seen as being especially problematic and was a concern because of the problems it would create for their families.

Secondly, young people wanted to discuss how their condition might impact on key aspects or milestones in their lives, for example, socialising with friends, school, university, careers, relationships, safe drinking and pregnancy. Young people were strongly engaged by the idea of contextualising self-care to all these issues. Thirdly, body image and self-esteem were highlighted as important issues, especially

maintaining a healthy weight and exercise in relation to the condition, engaging in sports and having the confidence to socialise. Fourthly, young people wanted an opportunity to discuss how they might tell others about their condition. They were also interested in acquiring skills to allow them to speak more functionally with health professionals. Finally, there was a desire to learn new techniques to become more confident in dealing with their condition and to be more autonomous.

Views on the delivery of a self-care programme

Young people in our sample had definite views relating to the way in which a self-care programme needed to be delivered. A priority for them was that the programme should be fun, i.e., 'not boring' and not at all like formal, school-type lessons. Whilst discussing programmes that would not be boring, expressions such as 'doing things' were regularly repeated. There was strong interest centred on providing a wide variety of different activities as part of the programme. Importantly, young people stated that they needed to be listened to and they wanted the opportunity to talk with other young people with the same condition. Being 'lectured to' by adults was regularly described as being unacceptable. Instead, their preference was to meet with others of a similar age, in small groups and without being overseen by parents or health professionals.

In terms of when young people wanted to attend a programme, they said 'regularly after being diagnosed', outside of school time and preferably at weekends. Ideas for a programme venue included leisure or music centres, but definitely somewhere within easy access to home. Young people were adamant that they did not want to meet at school, home or hospital.

The self-care intervention

Following the analysis of the talking group transcripts and the identification of the main themes, young people and young adult facilitators worked alongside the researchers to design some prototypes of interventions that could provide the basis of a self-care programme before deciding on a final version. In this way, key themes from the talking groups were linked to individual workshops, with each workshop addressing an overarching topic that the young people felt was important. For example, young people highlighted communication as a significant issue in the talking groups and they wanted a workshop on this within the intervention. Therefore, a workshop focused on communication strategies, together with parental, professional and peer relationships and their impact on young people's ability to self-manage, was developed. Similarly, young people identified key lifestyle issues (e.g. socialising with friends) and significant milestones (e.g. going to university), as topics for inclusion in another workshop. In this workshop young people wanted practical information and strategies on how to manage their condition whilst also living normally. Additional workshops were built around the themes of a positive body image and developing greater confidence to manage a chronic condition.

The next stage involved working alongside the young people who had taken part in the talking groups to decide on the format of the workshops and to ensure that they accurately reflected what they wanted in their self-care programme. After numerous iterations, the intervention comprised a series of five self-care workshops focusing on the key topics and strategies identified above. Workshop five was added following discussions with the young people about the importance of providing an opportunity for young people to reflect upon and assess the intervention. Young people felt this

was necessary for the continued development of the self-care programme and most importantly, to ensure it remained tailored to the young people's needs.

The formative research process resulted in a final intervention prototype, comprising five workshops:

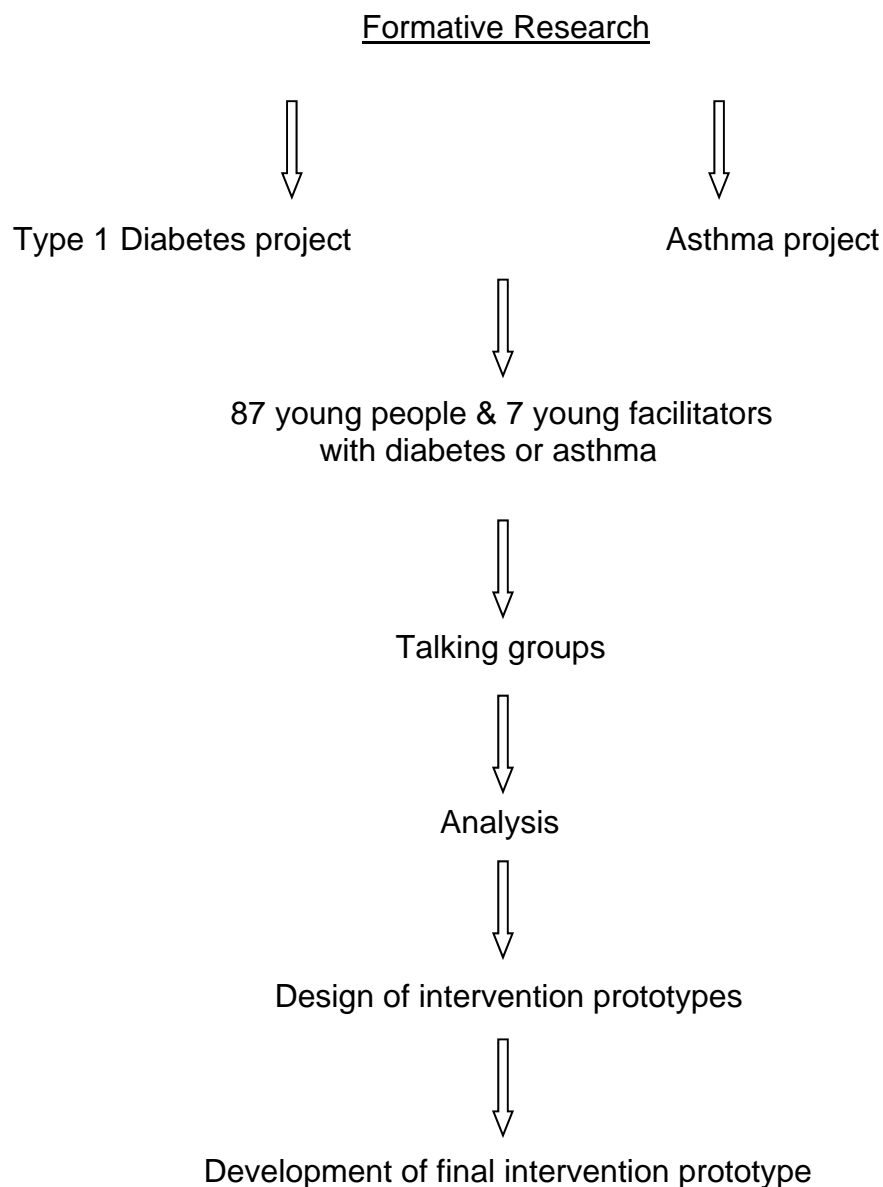
1. Knowing each other: to ensure participants feel safe and comfortable in a group setting so they can work collaboratively;
2. Managing the condition: to acquire condition-specific knowledge and skills, so they can feel more in control of their condition, be more responsible for themselves and therefore, become more independent;
3. Communication and relationships with others: to improve relationships with peers, family and professionals and develop more effective communication strategies;
4. Feeling good: to enhance participants' self-esteem and work towards a positive body image, focusing on future 'life' events and practical advice on managing the condition;
5. Evaluation: to allow participants and facilitators to reflect on their journey through the workshops and capture the benefits of taking part, including the ways in which the workshops have impacted on self-care skills.

These initial workshops incorporate a balance of activities: practical and fun-based pursuits to establish trust and build up rapport; discussions focusing on key aspects of living with a chronic condition and specific exercises relating to type 1 diabetes or asthma, predominantly relating to psychosocial issues. This prototype intervention

does not focus exclusively on the pathological aspects of the condition, but encompasses a more holistic approach. For example, it includes the impact that type 1 diabetes or asthma has on a young person's life and those around them, generating strategies and solutions for dealing with the issues they may face so they are able to self-manage in ways that suit them. To complement their aspirations for delivery 'style', the workshops are guided by three fundamental principles:

- Empowerment: being enabled to develop knowledge, skills, understanding and motivation in relation to their condition;
- Self-efficacy: taking responsibility for their condition and their lives;
- Engagement: fully engaging in proactive management of their condition.

Stages in the development of the self-care intervention prototype.



Discussion

This paper has presented the results of a formative research study aimed at developing a self-care intervention programme for young people living with the chronic conditions of type 1 diabetes or asthma. It has described the design and development of an original intervention aimed at this population group, but most importantly, it has highlighted the essential role that young people have played in the

developmental process. Inevitably, the evidence presented here is indicative, rather than definitive, of what young people want, but most importantly it is client-based rather than aligned to a professional or adult agenda. Although programmes for young people exist that are led by peer-educators [25, 26] they have been developed by adults and there is no sense of ownership on the part of the young people.

Furthermore, although it is not possible to confirm whether the evidence from this multi-site study is representative of all young people of a similar age with diabetes or asthma, the findings, in particular those relating to self-management strategies and increasing levels of independence and self-worth, are consistent with other studies involving young people with a chronic condition [15, 24, 25, 26, 44]. Principally, this study re-affirms the value of refining client-centred services to meet the expressed needs of young people with a chronic condition and in so doing, using the adolescent years as a window of opportunity to re-orientate services, thereby ensuring young people are assisted to become successful adults in the NHS healthcare system [45]. In addition, it suggests that the concept of engaging young people in service re-development should be an integral component if self-care programmes are to meet the needs of this population group and improved self-care outcomes are to be achieved.

The most surprising outcome from the research, and one which sets it apart from earlier studies, is that young people expressed a clear preference for making 'life as an adolescent' a priority within the content of the intervention; they did not focus on type 1 diabetes or asthma as an 'illness'. This has important implications for practice in terms of self-care and service re-design. The research described here clearly demonstrates the need for a new approach towards self-care, one which is centred on the chronic condition in the context of a young person's life rather than one that is

predominantly and obviously medically-focused [27]. Young people wanted to know how they could use medical advice to support as normal a daily life as possible, whereas they were concerned that existing services were expecting them to give up on the activities that they could share with friends. Preliminary evidence indicates that the intervention described here is not only different to conventional medical approaches, but also is making a difference to young people's lives, especially in terms of young people's aspirations to stay out of hospital and to develop a more normal lifestyle while at the same time managing their condition. However, rising to the challenge and reorienting services towards an approach that is innovative and largely unexplored in the UK may prove to be difficult, especially when an established, albeit ineffective, approach already predominates. That is a traditional model of patient and professional interaction with conversation focusing only on disease maintenance, which is not sufficient to ensure young people are adequately prepared to take on their adult self-care responsibilities.

Nevertheless, a failure to respond to the participant 'voice' is proving costly, in particular given the latest evidence demonstrating that deaths from diabetes could be prevented through better management [46]. The National Diabetes Audit clearly shows substantial gaps in existing services, primarily relating to psychological support, structured education and transition [14]. More generally there is a lack of provision for facilitating self-care amongst young people with chronic conditions, including diabetes and asthma. Therefore, a strong case exists for taking the intervention developed through this formative research and pre-testing it as part of a larger scale delivery. The total number of young people with type 1 diabetes or asthma is small in absolute terms. This means that the piloting of the intervention has to be conducted on a large scale in order to capture young people with these

chronic health conditions. Indeed, further work is needed, not only to evaluate the intervention and assess its value for improving outcomes for young people with type 1 diabetes and asthma, but to determine the transferability of the model to other chronic conditions.

Limitations

Data on sample and illness characteristics were not collected beyond the age, sex and chronic health condition of the young people involved. As such it may not be possible to generalise the findings to the wider population of young people with type 1 diabetes or asthma. The focus of the self-care intervention is on meeting the psychosocial needs of young people with type 1 diabetes and asthma. Whilst this may be considered to be a drawback of the intervention, a focus on psychosocial support addresses an important gap in service provision and at the same time complements the care young people receive in clinic. Since young people are able to obtain medical information from their clinicians it was not necessary to make this a key focus of the intervention. We acknowledge that the self-care intervention presented here is not a definitive model and further refinement is needed, but it is an original prototype where the approach taken, as well as the outcomes achieved, represent a major step forward in the design of a tailor made self-care programme for young people with a chronic condition.

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